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Involving young disabled children in the research process

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Abstract:

Young disabled people are still rarely involved in the research process, despite an increasing emphasis on their inclusion as participants. The Participation in Education (PIE) project examined how disabled children with little or no speech could be involved in their education. The project team worked with an existing group of young disabled people to develop ways in which they could take part in the research process. The group was involved in developing the methodology, group work, observation, commenting on findings and in the dissemination process. Their involvement undoubtedly enriched the research and the benefits of working with an established group were manifold.

Introduction

Until recently, it has not been usual for young disabled people to be consulted in research, let alone be active participants in the research process. In the UK, the requirement to ascertain the views of children began with the 1975 Children Act and was reinforced in the Children Act 1989 (Franklin and Sloper 2004). Subsequent policy initiatives and increasing skills in this area have led to a greater involvement of children, including disabled children, in research and policy development (Alderson, 2008), but there is still work to be done in this area to make it a meaningful exercise. Disabled people are increasingly involved in research that affects their lives, although they are still rarely in control of the research process, the ideal that Barnes suggested we should strive for (Barnes 2001). However, young people with communication and/or complex disabilities are seldom included in the research process, even as participants (Watson et al 2007, Morris 2003) and this study provides an attempt to address this imbalance.

The Participation in Education (PIE) project demonstrates that young disabled people can be effectively involved in the research process in research with disabled children with little or no speech (Feiler and Watson 2010). This article will focus on aspects of the project that were carried out in partnership with young disabled people, followed by a discussion of the challenges, tensions and advantages of working in this way. A

discussion of the findings relating to teachers can be found in Feiler et al (2010) and details of the outputs from the study will be found below.

The Participation in Education (PIE) project

The aim of the PIE project was to look at ways in which disabled primary school age children with little or no speech could be more involved in their education. This included looking at both 'formal' decision-making processes such as Reviews and Individual Education Plans as well as informal aspects such as peer interaction. The two-year project was funded by the Esmée Fairbairn Foundation.

The project involved 11 primary school age disabled children who had little or no speech. They all attended one of two special schools in the South West of England. Prior to the children being recruited, a national survey was conducted to identify practice that was of interest regarding involving children with little or no speech in their education. Family members were also interviewed and interviews were conducted with teachers, teaching assistants, head teachers and speech and language therapists who were 'around' each of the 11 children. The main messages that arose from the study were:

- Children are increasingly successfully involved with their reviews, school councils and target setting
- Children can be included in all aspects of decision-making at some level, given the right support and motivation
- An increase in whole school and Local Authority approaches to communication is needed, to ensure continuity
- More training and support with communication is needed for professionals, families and, in particular, for teaching assistants as they play a key role in supporting communication
- An increase in sharing of good practice is needed, both within and between schools and between families and schools
- The funding and insurance of communication aids is an issue that needs to be addressed to ensure equity

As a result of this study, a resource pack was produced which can be found at:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/iwanttochoosetoo.pdf>

In addition, the 'messages' from the study can be found in a booklet at:

<http://www.bristol.ac.uk/norahfry/research/completed-projects/pie-messages.pdf>

Theoretical background

In order to provide some background as to why we felt it was important to involve young disabled people in the research process, it is necessary to explain our theoretical stance. Emancipatory and participatory disability research paradigms have emanated from a social model of disability, and have roots in Critical Theory and the Frankfurt School in the 1930s. The defining characteristic of Critical Theory is the aim to be more than just a theory, to be a philosophy that is embedded in the 'lived reality of social life' (Crotty, 1998 p.131) and which brings about positive change. Usher (1996) describes the term 'critical' as referring to the:

'..detecting and unmasking of beliefs and practices that limit human freedom, justice and democracy' (p.22)

We were mindful at the outset of this research that we had a clear agenda for change, recognising that disabled children with communication and complex difficulties are often excluded both from research and participation in society generally (Morris 2003, Townsley et al 2004, Rabiee et al 2005, Watson et al 2007). In carrying out research with children who can all too easily be overlooked, we needed to recognise the difference in the power relationships between ourselves as researchers and the participants. This 'fits' with disability research that is carried out within a social model where the power relationships between researcher and researched are sought to be minimised. Social models were influential in our research because they enable us, as Davis et al (2008) state:

'.....to move beyond notions of disabled children as medically defined unchanging individuals' (p.222)

We held the view that the children in our project were active 'meaning makers' who could negotiate different settings (Nind et al 2010). However, we were also aware that we needed to be conscious of the particular difficulties that these children had due to their impairments. We therefore adopted an 'interactive' approach, as described by Shakespeare (2006) who calls for a model which acknowledges the *interaction* between individual and structural factors and the relevance of disabled people's impairments on their lives.

There are many, differing views on the distinctions between participatory and emancipatory research (Barnes 2001, French and Swain 1997). We suggest that the PIE

project cannot claim to be emancipatory in nature as it did not emanate from disabled people (Barnes 2001), and the control of the project was largely held by us as university based researchers. We needed to be realistic about what could be achieved within budgetary and other constraints. As far as we were aware, no other projects had attempted to involve young disabled people in research with disabled children with communication difficulties and so we were 'feeling our way' in this respect. We had budgeted for the involvement of young disabled people as a reference group and were open-minded as to what this might involve. It could be said that our approach was participatory in that we worked closely with this group and, in addition to this, as we will discuss in more detail later, we involved two young disabled people who were part of the group as co-researchers. We were aware of the challenges in carrying out research with children with little or no speech and sought the advice and involvement of young disabled people, partly as a way of gaining an insight into power relationships. We had a genuine belief that young disabled people could make a unique contribution to the project, by reflecting on their own experiences of being young and disabled and in what ways they had felt included or excluded when they were at school, and by drawing on these experiences to guide aspects of the project. Before starting to work with the group, we were not aware of the impairments that the young people had, other than that there would be young people with a range of difficulties and that they would have support to communicate, where needed. The involvement that developed was therefore an iterative process, with the project workers and the group coming together in a working relationship that was based on mutual trust as time went on. Although the researchers could be criticised for not having involved the young co-researchers in all of the fieldwork, we felt it was a step in the right direction, and would (and has) lead to further involvement in future work.

Working with the group of young disabled people

We approached a group of ten young disabled people aged 13 to 25 that was well established in the city in which we were based and which we were made aware of by one of our research advisors. The group continues to meet weekly as a social group but also as a forum to discuss the rights of young disabled people. Organisations are invited to consult with the group with the aim of giving young disabled people a voice in making decisions. We decided early on in the project that it would be preferable, and more ethical, to meet with a group of young disabled people that was already established rather than setting up a group that then may be disbanded at the end of the project.

The use of reference groups in research with disabled people, including the PIE project, is discussed in Lewis et al (2008). We were fortunate that this particular group indicated, via contact with their facilitator, that they were keen to work with us. We

met with the group facilitator prior to the first meeting to establish that we would pay costs for the meetings that we attended, including support costs and travel and went over some 'ground rules'. The facilitator was happy with our 'open' approach to what the involvement of the group might specifically entail. As well as the (approximately ten) young people, a facilitator and several support workers were present at each of the subsequent meetings, although the personnel changed during the project.

Over the length of the project two of the project researchers made four visits to the regular meeting of the group of young disabled people. Each meeting lasted for about an hour and a half.

1. At the first meeting the researchers asked the ten young people about the different ways that they made decisions at school, we then organised them into pairs and asked them to convey something they liked, without using words. We listed the different ways that they communicated and what it felt like. We also asked them for their ideas about how to involve children with little or no speech in their education. They felt strongly that all young disabled people should be able to make decisions and that there should be better training for teachers and head teachers. They thought they should be able to vote on issues that affected them and that random Ofsted inspections would help to keep staff on their toes! Only one member of the group felt that s/he had been involved in making decisions at school. At the end of the session we asked in general terms if any of them would like to be involved in going to the schools as co-researchers. Several of the young people indicated that they would be interested in doing this.
2. The make-up of the second meeting was similar in that there was the same number of young people, but there were some changes in the group with a new member attending, another absent and a different facilitator. At this meeting we decided that we had to be very focussed in order to make the exercise work, so we recapped on the previous meeting, then verbally told them our 'job description' and 'person spec' for the role of co-researcher. We had written these beforehand and they consisted of very straightforward requirements such as 'To be in a classroom with Debby, watching a child who does not have any speech. To notice how often and in what ways the child is involved in making choices or decisions. To spend a bit of time with Debby after watching the child, talking about ideas about what went on in the classroom'. They decided to choose who should become a co-researcher by asking the young people that were interested to take turns and speak (with support where necessary) for a minute on why they would be good for the job and then the group would vote. Two young

people were chosen, having been voted for by the group. The work carried out at the school with the co-researchers will be discussed below.

3. At the third meeting one of the young co-researchers fed back to the group about how the visits to the special school went. Again, there were ten young people and another new facilitator. We had previously given the facilitator the main messages from the initial analysis of the work carried out with the young people (in the form of bullet points on large sheets) and they talked about some of them at the meeting and whether they agreed with what the young people in the research were saying. The facilitator had also sent some written feedback.
4. The final visit was to show the group the finished resource pack (Watson et al 2007), thank them and talk about future work. This was a slightly smaller group, but with the same facilitator as in the third meeting. We wrote a letter of thanks to the group that they could use in their publicity and fundraising.

In addition to these four meetings, the two young co-researchers attended two sessions at one of the special schools that we were working with. The first session was an observation session. One of the researchers and the two co-researchers met in the school lobby and went over what was going to happen in the classroom. They were each introduced to a child that was involved in the project and who had consented to take part. The two co-researchers were asked to observe how many times the children were given choices and what sort of choices they were. One of the researchers was also observing a child. The researcher and the co-researchers met again at the end of the session and the researcher took notes about the co-researchers' comments. The second time, the researcher and co-researchers again met beforehand but this time worked out together what questions would be asked of a small group of children with little or no speech who were part of the project. An approximately fifty-fifty mixture of questions generated by the researcher and the co-researchers resulted. Turns were taken by the researcher and the co-researchers to ask questions and support was given by a teaching assistant who knew the children well. There was a 'debriefing session' at the end when the researcher took notes on the young co-researchers' observations. This meant that the young people acting as co-researchers did not have to do any writing, as they had previously expressed concerns about this.

Following the completion of the project, the co-researchers were invited to take part in a dissemination event at the University. Unfortunately, only one of the co-researchers was available to take part in the presentation. One of the researchers met with the co-researcher before the event and it was decided that a 'question and answer' format would work best for her because she had good recall but was not

confident about reading from a script or notes. This made the presentation quite challenging, but possibly more interesting to listen to than a script. The researcher asked questions such as 'what did you notice about the children when you were observing in the classroom?'. The co-researcher was then able to talk about what sort of decisions and choices the child that she was observing made. This co-researcher has since gone on to help with teaching sessions on several University courses and has worked on another research project with one of the researchers as a co-researcher.

Discussion

As mentioned above, the involvement of the young disabled people in the research process was part of the iterative approach to research design, planning and research questions taken in this study, where these aspects constantly interact and evolve to lead critically to the central issues (Clough and Nutbrown 2007). This allowed for flexibility and an ability to adapt to the circumstances in which we found ourselves, but inevitably involved some challenges as well.

Challenges

Overall, the involvement of young disabled people in the research was invaluable, in ways which we will discuss below. However, it would be dishonest to ignore some aspects that made the process more challenging than research that does not attempt to work in an inclusive way.

Focus, motivation and function of the group of young disabled people

One of the initial difficulties that we faced was in focusing and motivating the group in the first meeting. We attempted to do this in an interesting way by engaging the young people in interactive activities, but even so the session was noisy and somewhat unfocused. On reflection, we felt that in part, it was our lack of clarity and desire to be 'open' to what we wanted from the young people that caused this. We also were aware that the group facilitator at this stage adopted a 'hands off' approach which the young people were used to and we were not! This meant that the management of the session was largely left to us and we had to do a lot of 'thinking on our feet'. The way that the group was used to working, the personalities and support needs of the members were unfamiliar to us, other than what we had learnt in our initial meeting with the facilitator. In addition, it was quite intimidating to work in a group where there was a relatively large number of support workers, who also had varying approaches to working with the young people. Rather than be judgemental or daunted by this, we had to accept that these workers knew the young people a lot better than we did and the group was used to working in a certain way that we had an obligation

and desire to respect. This experience made us concentrate on how we could work with the group in a meaningful, non-tokenistic way in the subsequent sessions.

It would have been possible simply to work with this group in a more traditional, purely advisory role and this would have had value in itself. However, it became clear after our first meeting that several members were keen to work in a more 'hands on' way and several members of the group indicated that they would like to accompany a researcher to one of the schools. We saw this as an opportunity to be grasped as we were convinced, having heard their contributions in the initial meeting, that they could bring a unique perspective to the study that we, as non-disabled researchers did not have. We were fortunate in that the school was also agreeable to this, as it did mean that three extra people would be in the classroom rather than just the one that they had originally expected.

Choosing the co-researchers

Our early experience with the group made us aware that we needed to be a lot more specific about what we wanted from the group and this resulted in the development of the job description and 'person specification' that were successfully employed in session 2. The method of choosing the co-researchers was an approach that seemed to us quite intimidating and 'high risk', but the group were used to working in this way and the outcome was a good one for us in that the young people that the group chose appeared to us as researchers to be suitable for the task and keen to take part. It would have been very difficult to have to challenge their choices but fortunately we were not put in the position of having to work with someone who we felt would struggle with the job description. We felt that this outcome was due to the way that the group had evolved and worked together in the past. So, even though there was some risk involved in going along with their way of working, we were helped by having confidence in the group and the way in which they operated. As a realistic and clear job and person specification had been developed by the research team, this made the skills and experience needed explicit, which also helped to reduce the risk of a difficult choice being made. If we had been in the position of having to suggest a different choice of co-researcher, having built up a relationship with the group it is hoped that this could have been negotiated openly, without jeopardising the working relationship that we had established. The co-researchers did not match the group of children that were the focus of our research, 'children with little or no speech', as the co-researchers were teenagers with a degree of learning disability, one of them being a wheelchair user. They both had considerable contact with children with communication difficulties previously and it was clear from the initial meetings that they were familiar with and sensitive to the potential issues. It would, we believe, have been unrealistic to try work with the same group of children as a reference group as

the children in the project were not only very young (primary school age) but would find it extremely challenging to fully understand the role expected of them and express themselves. However, we should acknowledge that it feels uncomfortable to write this, and maybe in the future it may be possible to find a way of matching the groups more closely.

Time issues

Supporting the young disabled people in their tasks in the school inevitably led to the researcher having less time to devote to her own observations and contribution to the group session. It took considerable time to set up the sessions, with liaison between the young people and, in one case, her family to arrange lifts and for the other young person to arrange a taxi to get her to the school. During the sessions, the researcher was constantly aware of the young people and whether or not they were comfortable with what they were doing as well as whether the teacher, other staff and the children were also content with what was happening. Time was spent in the school both before and after the session with the young people, preparing for and then discussing the sessions. This was essential for the smooth running of the sessions and was positive in that it allowed the young people to contribute their own questions in an immediate way, where they were in the school and had more of an idea about the task than if we had planned the session further in advance, in another setting. As the idea of the young people coming to the school had evolved, rather than been planned for in the research design, it was not possible to extend their involvement beyond the two sessions without having an impact on the rest of the project. For us, this was a lesson and in future work the detailed role of a reference group could be worked out at an earlier stage, although acknowledging that it is sometimes difficult to foresee how a project will develop. There can be advantages to working in an iterative way as it is good to be able to adapt to the group that you are working with, but it is certainly the case that more time needs to be written in to the research design than we allowed.

Tokenism

A common criticism of participatory research is that it can become 'tokenistic' and that the disabled people involved can become what are known as the 'usual suspects' in that once they are known to researchers, they are frequently asked to participate (Lewis et al 2008). We believe that we avoided these pitfalls in that neither of the young co-researchers had done this type of work before and they were chosen for the task by their peers. The advantages in working with an established group were very apparent in this respect, as they had processes and policies in place that made the selection process very successful. The training that they had received in Disability

Awareness and Equal Opportunities was invaluable as they were very respectful of each other and inclusive in their approach. As Frankham (2009) states:

'These groups are likely, already, to have debated the tensions associated with representing others and have agendas for action based on their on-going work.... In that sense, these arrangements are perhaps more likely to result in shared agendas for action.' (p.9)

Adopting this approach can mean that the disabled people that become involved in research are already, to some extent, 'politicised'. This is an inevitable result of being involved in awareness training and in a group that is disability focussed. We would argue that this is an advantage, especially when working with young people, as it means that the co-researchers are more likely to be aware of issues such as 'turn-taking' in discussions and treating other people with respect and courtesy. In our experience, it also meant that the young people were confident about expressing opinions and stating what their support needs were. It was also invaluable to have the support of the group with some personal issues that arose with one of the co-researchers.

Outcomes and impact

When considering what impact the involvement of the young disabled people had, it is challenging to provide an exact account. The young disabled people undoubtedly had an effect on some specific outcomes of the research. They added their own perspectives and insights in the meetings and the two co-researchers made insightful and original observations on their time spent with the young people. For example, they were struck by the use of humour in the classroom, and the fact that one of the young participants was able to play tricks with his voice output communication system (VOCA). This resulted in the researchers reflecting on this 'playful' aspect of young people with communication difficulties and how it is often lost in the myriad of curriculum demands and physical needs and this need to acknowledge playfulness became one of the 'messages' from the research. Other tangible outcomes reflect the closeness of the young disabled co-researcher's experience to that of the children in the study. The young co-researchers were comfortable with the children in the classroom, partly because they were nearer to that experience themselves but also, in the case of one of the co-researchers, she had previously attended the school so was familiar with the surroundings and able to answer some of the questions that the other co-researcher had. This, in turn, had an effect on the children being studied. Although they remained focused on the task, the young co-researchers were lively and cheerful, and seemed to make the children feel at ease and unthreatened. It is also the case that the young co-researchers thought of questions which the researchers would

not have come up with, and which have had an impact on subsequent research. For example, one of the co-researchers (someone who was a wheelchair-user) asked if the children in the group session would like to choose when to come out of their wheelchairs. As non-wheelchair users, the researchers had not thought of this as an area of choice, but the children all indicated that they would like choice about this and it proved to be an important finding for the PIE project and also as an aspect in a subsequent study.

However, the group did a lot more than affect specific outcomes – they influenced the study in a more nebulous sense that is difficult to quantify. They were a constant reminder to the researchers that their own perspective was not the only one, and the need to be accountable to the group was important in keeping the research grounded and focused. In reflecting on how the group's involvement developed, it has become clear to us that we know the research would have been poorer without the group's involvement, but we struggle to say exactly why. The role that the group and the two co-researchers adopted evolved gradually, through the interaction between the group and the researchers. Being mindful of power relationships meant that although the researchers led to some extent, in that they developed the job descriptions and designed the research, the group had autonomy about choosing the co-researchers and, in turn, the co-researchers had the freedom to ask questions that they wanted to ask, broadly interpreting the researcher's remit about choice. A tentative question about 'who might like to come to one of schools with me?' developed into a useful and worthwhile aspect of the research and the working relationship developed from mutual uncertainty to a mutually beneficial, respectful partnership where the research was the shared focus.

Conclusions

Working in this way, with some details of the research process being worked out with the young co-researchers 'in situ' was challenging in some respects, as we have seen. However, it was also stimulating for us as researchers and required an increased use of initiative which was refreshing and exciting. As Lewis et al (2008) state, if more disabled people can be involved at the 'weak', that is, participatory level, the more possibility there is of them going on to be involved at the 'strong' level, where they control the research agenda. The young co-researchers in this project had been through a disabled-led selection process, and this, together with the back-up of an established disability organisation were reassuring aspects, meaning that we were free to concentrate on the research process in order to get the best outcomes that we possibly could for this group of under-researched and often overlooked children. Recent ESRC seminars on 'researching the lives of disabled children' (ESRC 2010) reflect the emerging view that researchers should not just focus on innovative

methodology and congratulate themselves that disabled children are included in research, but research must also produce outcomes that are positive for disabled children. As a result of this project, at an individual level, one young disabled person went on to grow in confidence, be involved in teaching a group of masters level students and present at conferences. Who knows what she might do next? Even if that is all that this project achieved, and we believe it achieved a lot more, then it has to be worthwhile. The PIE project resulted in a resource pack that was widely used and appreciated (Watson et al 2007) and which was considerably improved by the contribution of a group of young disabled people who saw the importance of being involved in research from which they may or may not directly benefit, but which could benefit disabled children in the future. .

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